

Medical decisions concerning the end of life: a discussion with Japanese physicians

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Abstract

Objectives – Life-sustaining treatment at the end of life gives rise to many ethical problems in Japan. Recent surveys of Japanese physicians suggested that they tend to treat terminally ill patients aggressively. We studied why Japanese physicians were reluctant to withhold or withdraw life-support from terminally ill patients and what affected their decisions.

Design and participants – A qualitative study design was employed, using a focus group interview with seven physicians, to gain an in-depth understanding of attitudes and rationales in Japan regarding medical care at the end of life.

Results – Analysis revealed that physicians and patients' family members usually make decisions about life-sustaining treatment, while the patients' wishes are unavailable or not taken into account. Both physicians and family members tend to consider withholding or withdrawing life-sustaining treatment as abandonment or even killing. The strongest reason to start cardiopulmonary resuscitation – and to continue it until patients' family members arrive – seems to be the family members' desire to be at the bedside at the time of death. All physicians participating in our study regarded advance directives that provide information as to patients' wishes about life-sustaining treatment desirable. All expressed concern, however, that it would be difficult to forgo or discontinue life-support based on a patient's advance directive, particularly when the patient's family opposed the directive.

Conclusion – Our group interview suggested several possible barriers to death with dignity and the appropriate use of advance directives in Japan. Further qualitative and quantitative research in this regard is needed.

Introduction

Recent surveys of Japanese physicians have been suggestive of attitudes toward life-sustaining treatment and advance directives in Japan. A comparative survey of 136 Japanese and 77 Japanese-American physicians revealed that Japanese physicians tend to treat terminally ill patients significantly more aggressively than Japanese-American physicians. The same survey showed that Japanese physicians are often unwilling to discontinue life-support despite the patient's wishes.¹ Another study done in a teaching hospital in Tokyo regarding do-not-resuscitate orders (DNR orders) demonstrated that some resuscitation procedures were performed despite explicit orders not to do so. The rate of overriding DNR orders depended on whether attending physicians and patients' family members were present at the bedside.² A survey done by the Ministry of Health and Welfare revealed that 1,122 of 1,587 (70.7%) physicians surveyed stated that they would be willing to respect patients' advance directives for medical care at the end of life.³

Very few studies, however, have been undertaken which explore in depth the reasons why Japanese physicians treat terminally ill patients aggressively and what affects the physicians' decisions. Also, there has been no research done to investigate the appropriateness and problems of advance directives in Japanese culture. Our qualitative study was initiated to develop an in-depth understanding of Japanese physicians' attitudes towards life-sustaining treatment and advance directives. We strove to explore possible barriers to utilization of advance directives in Japan.

Methods

A two-hour group interview was conducted by two of the authors (A Asai and O Inoshita). In the interview, physicians were asked about current practices regarding life-sustaining treatment in their institutions and what protocols were used to initiate life-sustaining treatment for terminally ill patients.

Key words

Life-sustaining treatment; advance directives; Japan; qualitative study.

The interview also inquired as to the physicians' attitudes towards advance directives and possible barriers to using them in the clinical setting.

Subjects

Seven Japanese physicians were recruited from six different medical institutions; all were male, ranging in age from 31 to 41 years old. All were internists who treat patients with cancer and other serious diseases in daily, private practice. They did not know each other prior to the interview. Four of the participating physicians had spent a few years as researchers in France or the United States. Three of them were particularly interested in medical-ethical end-of-life issues. Six of them had between two and ten patients who had died of cancer during the past six months.

Results

LIFE-SUSTAINING TREATMENTS

The participating physicians revealed that it was very unlikely for terminally ill patients to be informed of their medical status: (For the most part the italicised comments which follow represent the views of all respondents. However, in some instances, they are quotes from a single physician.)

When we find an advanced cancer, we contact the patient's family members in order to explain the diagnosis and prognosis to them first. We also ask the family members whether we should disclose the information to the patient. In many cases, the family asks that we not disclose a diagnosis of cancer to the patient.

Decisions at the end of life were usually made without consulting patients to find out their explicit wishes or intentions. The physicians revealed how they made decisions regarding life-sustaining treatment. All participating physicians admitted to a common experience:

The patient's family or the family members and physician together usually make decisions whether or not to provide a terminally ill patient with life-sustaining treatment. It is very rare for even a competent patient to participate in these decisions.

Often the patients' wishes about prolonging life were not obtained when such decisions had to be made because the patients were no longer competent:

Many of my patients are in a coma when we have to decide whether to prolong life. In many cases the patients are incompetent and cannot make decisions.

Different physicians had different approaches to the disclosure of a diagnosis of cancer and to informed

consent. One of the physicians participating in the interview opposed the procedure of informing the family first:

It is not appropriate for physicians to disclose the diagnosis of cancer to a patient's family first. We should tell the patient first because it is the patient who has the cancer. In my institution, we have disclosed the diagnosis of cancer first to almost all our patients, say in 99% of cases. I explain the precise prognosis to my patients when they ask for it.

This physician explained why he believed he ought to disclose the truth:

I do not know whether disclosing a cancer diagnosis is absolutely right or not, but I need to explain the diagnosis, prognosis, and effectiveness of treatment to my patients. Chemotherapy usually requires two months' treatment to prolong a patient's life two more months. Some patients would not want to undergo such chemotherapy. So, I must explain all relevant information to them so that they can avoid unwanted treatment and stay out of the hospital.

One possible explanation for these inconsistent attitudes among physicians was given:

There is neither open discussion nor a written policy regarding how and how much information should be given to patients with serious illnesses. Ethics committees in Japan do not discuss individual cases in regard to the appropriateness of prolonging life.

The physicians revealed their attitudes towards life-sustaining treatments:

Even when life-sustaining interventions for a competent but moribund patient turned out to be futile, we never asked the patient whether we should discontinue the interventions. In reality, it is extremely rare for the medical team in charge to take the initiative to withdraw life-sustaining interventions from any patient.

The physician who usually disclosed the diagnosis and prognosis of cancer to his patients also discussed life-sustaining treatment with his patients:

I explicitly recommend to my patients with terminal lung cancer and respiratory failure not to undergo intubation. Intubation cannot make my patients more comfortable. I have no desire merely to prolong my patients' lives. I just want to make them comfortable.

One participating physician had actually been asked by the family to extubate a moribund, unconscious patient:

I did not do it.

The physicians gave the reasons why they were unwilling to withhold or withdraw life-sustaining treatment from patients with terminal diseases, even the moribund:

Withholding or withdrawing life-sustaining interventions, haemodialysis for example, is a kind of abandonment.

All comfort measures sometimes failed to control a patient's severe distress. Even in such cases, physicians and the patient's family members did not discuss withdrawal of life support:

One of my patients with renal failure had uncontrollable pain and nothing could alleviate his distress. He was competent and asked me to kill him. His family asked me to make him comfortable, but they could not tell me to discontinue his haemodialysis because such a request would mean the abandonment of the patient. They were horrified at the possibility that the patient might think his family had abandoned him, although discontinuing life-support would have been consistent with his wishes. I started morphine to decrease his level of consciousness, but continued haemodialysis until low blood pressure made it impossible. I never discussed the discontinuation of dialysis with the patient. I believe that stopping dialysis is abandonment.

Some regarded discontinuation of life support as euthanasia:

Euthanasia is illegal in Japan, so I cannot stop any life-sustaining interventions once they are begun.

Fear of legal liability was also mentioned:

Some patients' family members would accuse us of killing the patients if we stopped artificial ventilation or haemodialysis.

Those who were willing to withdraw some life-sustaining treatments would do so gradually:

I have never stopped artificial ventilation for patients who are moribund, but it is possible to decrease the oxygen level of ventilators for such patients little by little. No one would "pull the plugs", although many may withdraw life-support slowly using subtle measures.

Family members' requests influenced the physicians' medical decisions at the end of life:

In Japan, consensus has not yet been reached on life-sustaining treatment. I have had the experience of some family members asking me to prolong a terminally ill and unconscious patient's life until the rest of the family members could arrive at the bedside. Artificial ventilation was initiated, and I did everything possible until the patient died.

Whether to perform cardiopulmonary resuscitation is an important issue. Prior discussions with family members made a significant difference:

It depends on having a prior discussion with the patient's family members about what course to take in a situation of cardiopulmonary arrest. If it happened before any discussion, we would do it.

Whether or not the patient's family was present at the bedside when cardiac arrest happened was also significant. The physicians revealed why:

I would not perform CPR if the family members were at the bedside. In some families, it is very important to be there when the patient passes away.

Some families evaluated the attending physicians' sincerity based upon how they treated the dying patients:

Cardiopulmonary resuscitation is an important ceremony for some families. We are expected to do something at the end of the patient's life.

ADVANCE DIRECTIVES

The physicians disclosed their attitudes towards patient self-determination and advance directives:

I would regard patients' wishes about life-sustaining treatment expressed in advance directives; their self-determination should be respected. It is our role to evaluate patients' medical situations, but we should also respect patients' decisions regarding whether or not to undergo life-sustaining treatment.

The interviewees thought advance directives would be useful in setting the parameters for care at the end of life:

Advance directives may help us determine our aims in medical care at the end of life. An advance directive could be useful in resolving any disagreement between physicians and family members. We could discuss what to do based on the directive.

One physician thought that an advance directive should be a voluntary expression of a patient's wishes:

I oppose the universal usage of it as in the United States. It is preferable for patients to prepare it by themselves voluntarily. And if such spontaneous directives were presented to me, I would respect them.

Several physicians who supported universal use of advance directives indicated several barriers to practical implementation. They considered family wishes to be one such significant barrier:

It would be difficult for me to follow a patient's wishes,

expressed in an advance directive, against the family members' wishes to prolong the patient's life. We have to protect ourselves from conflict. It is the family that physicians must deal with after the patient dies. The fact that a physician acted upon explicit patient wishes given in an advance directive would not be enough to protect him or her from blame or a lawsuit filed by the family. Even if the law recognized the validity of patients' advance directives and granted us legal immunity, we could not avoid the agony we would feel in acting against patients' families.

Some indicated that the situation worsened when family members disagreed with each other regarding prolonging the patient's life:

Family members' wishes concerning prolonging a patient's life differ. Close relatives who take care of the patient every day tend to prefer less aggressive management and a peaceful death, while other members who live far away from the hospital request us to prolong the life of the patient as long as possible.

One physician expressed discomfort with discontinuing life support:

I am willing to follow a patient's advance directive, but withholding life-sustaining interventions is one thing; withdrawing them is another. It would be no problem if the advance directive instructed me not to initiate life-support in the first place; however, it would be emotionally disturbing to discontinue artificial ventilation or vasopressor, for example, once they are begun. Discontinuation of life-sustaining interventions is taking action, and the boundary between euthanasia and the discontinuation of life-support is obscure.

There were several other concerns raised regarding the use of advance directives. When to discuss the issues was seen as an important factor:

Many patients I have taken care of have been incompetent when decisions to forgo life-support had to be made. However, I cannot imagine that I would discuss such problems with my patients when they are not terminally ill.

Another problem was constraints of time and staff:

Many patients will not be able to understand an explanation about advance directives. We need someone to explain the content of advance directives because many patients will not be able to understand the words used in them. And if physicians have to do the explaining, it would be nearly impossible. We do not have the time.

Discussion

Our qualitative study, employing a focus group methodology, was used to explore the reasons why

Japanese physicians treat terminally ill patients aggressively, and what affects their decisions. Attitudes and underlying reasons for and against advance directives were also explored.

The generalization of our results is limited. The group interview was held just once, and it is likely results would differ if we formed a focus group of other physicians with different backgrounds, for example age, gender, and specialty. The physicians who participated in our group interview are not necessarily representative of all physicians; approximately half of them were specifically interested in ethical issues related to terminal care and had experience of practising medicine in Europe and the United States. Their rationales could be progressive and westernized. However, the basic attitudes of the participating physicians and the current situations they described are consistent with available published data regarding life-sustaining treatment, DNR orders, and advance directives.¹⁻³ Although we cannot conclude that the reasonings expressed in this group interview are representative of all Japanese physicians, we believe our findings do shed light on family and physician decisions at the end of life in Japan, a non-Western society.

In 1992, the Japan Medical Association officially declared that patient wishes for death with dignity should be respected.⁴ The association also declared that forgoing and terminating life-support based on patient wishes or advance directives is ethically acceptable, and that physicians who do so are immune from legal liability. In our group, no participant held the belief that the end of life should be prolonged. They thought that advance directives providing for patient wishes concerning medical care at the end of life could be utilized in Japan. Nevertheless, the participating physicians still believed that withholding or withdrawing life-sustaining treatment was the same as abandoning their patients. Despite the official statement of the Japan Medical Association, the physicians feared family lawsuits or accusations of killing the patient. Our findings suggest that some Japanese physicians may regard withholding and withdrawing life-sustaining treatment as ethically or legally unacceptable, rather than regarding these measures as a means to a peaceful death with dignity.

The attitudes of patients' families as reported by the physicians revealed that patients' families might also share common, negative feelings towards forgoing or discontinuing life-sustaining treatment. It is likely that physicians' decisions are strongly affected by such attitudes. Decisions made jointly by well-meaning physicians and family members biased by a sense of guilt and fear would inevitably result in aggressive and endless life-prolongation. In the current decision-making process concerning care in Japan at the end of life, what is lacking is a way of knowing and following the patient's explicit wishes. Many other things take priority over the

patient's wishes, even when clarified in advance directives.

The possibility that medical costs and the reimbursement system in Japan might contribute to the present situation should also be mentioned, although no participating physician referred to this in the interview. Almost all medical treatments are free for patients over the age of 70 and for those over 65 who are bedridden. For younger patients, there is a ceiling on monthly co-payments, the portion paid by the patient.⁵ It is unlikely that the decisions of patients and their family members are significantly affected by problems of financial burden in terminal care. On the contrary, the problem of overtreatment of the elderly, particularly in long-term care, has been pointed out.⁵ Due to the low cost of medical care and fee-for-service payments, any hospital as a whole or physicians who own private hospitals or are not on fixed salary might have incentives to continue aggressive life-sustaining treatments. There has been no evidence or data so far, however, to suggest that financial incentives affect medical end-of-life decisions made by Japanese physicians.

This first group interview was suggestive of several possible barriers to death with dignity and the appropriate use of advance directives in Japan. Further qualitative and quantitative research regarding physicians' attitudes toward medical decisions at the end of life is needed to ascertain fully the reasons why physicians tend to continue aggressive life-sustaining interventions. We need to learn more about the attitudes of Japanese patients and their families in this regard. We also need to explore what kinds of terminal care patients in Japan want and to

what extent they want such care implemented. Another question which should be asked is how much patients would allow their family and their physicians to overrule their wishes.

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News and notes

Medical Ethics at the Close of the 20th Century

The Ministry of Science, State of Israel is to sponsor an international conference on medical ethics at the close of the 20th century. The conference will be held at The Van Leer Jerusalem Institute (5-8 January 1998).

Speakers include: Baruch Brody (Baylor College of Medicine); Tom Beauchamp (Georgetown); Raphael Cohen-Almagor (Haifa); Bernard Dickens (Toronto); Justice Dalya Dorner (The Supreme Court of Israel); Shimon Glick (Ben-Gurion); John Harris (Manchester); Govert den Hartogh (Amsterdam); Jan C Joerden (Europa-Universitat Viadrina); Eike-Henner

Kluge (Victoria); John Lantos (Chicago); Evert van Leeuwen (Vrije); Frederick Lowy (Concordia); John Robertson (Texas); Charles Sprung (Jerusalem); Avraham Steinberg (Jerusalem); Antonella Surbone (Memorial Sloan-Kettering Cancer Center), and Robert D Truog (Harvard).

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